GREATER INVOLVEMENT OF PEOPLE LIVING WITH OR AFFECTED BY HIV/AIDS (GIPA)

REPORT OF THE TECHNICAL CONSULTATION ON GIPA

February 28-March 1st, 2000

NAIROBI, KENYA

Joint United Nations Programme on HIV/AIDS
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TABLE OF CONTENTS

WHAT IS GIPA?

Overview from Paris AIDS Summit

The acronym "GIPA" was first orated during the preparatory meetings for the Paris AIDS Summit, held in December 1994. GIPA stands for the Greater Involvement of People Living with HIV/AIDS coming directly from the text of the Declaration[1]. The text suggests an initiative to strengthen the capacity of people living with HIV/AIDS (PLHA), networks of PLHA and community based organisations to participate fully at all - national, regional and global - levels, in particular stimulating the creation of supportive political, legal and social environments.

Over five years have passed since the Paris AIDS Summit and yet the concept of GIPA still needs defining. Why is this? In part, because effective GIPA will mean something different in every country and cultural context. Also - sadly - in large part because there is still a broad reluctance to expand the pool of decision makers - thus leaving the GIPA initiative a brilliant concept on paper, but with much work to be done to make it a reality. With this in mind, UNAIDS has undertaken not only the implementation of GIPA within its own work including in the staffing and governance of UNAIDS, but also the commitment to realise GIPA at all possible levels of work in HIV/AIDS. And, perhaps most importantly, the determination to encourage meaningful GIPA initiatives amongst all of its collaborators be they governments, private sector, bilaterals or community partners.

UNAIDS Working Definition

UNAIDS has broadened GIPA to include those most directly affected by the epidemic. This is done with the understanding that no one can speak for a person living with HIV except a person living with HIV. Nor can anyone speak for the bereaved widow or orphan of someone lost to AIDS, except someone with that experience, which is not necessarily that of all PLHA.

It is critical that we do not lose sight of the importance of GIPA-which is not to promote exclusivity of living with HIV- but rather to increase the effectiveness of policy and programming by including those living with the virus in their lives - with or without being infected - at all decision making levels.

As with many difficult tasks of our time, UNAIDS finds itself confronted with the dilemma of the wish to have strict definitions and the necessity of being flexible enough to be effective in the response to HIV/AIDS. The virus, as we all know, is far from politically correct, thus UNAIDS asks if indeed we can afford the luxury ourselves. Clearly a topic of heated debate, the definition of GIPA remains worthy of discussion and, warranted a large devotion of time at the Nairobi Consultation to ensure that UNAIDS is in line with the desires of the community of PLHA and others most affected by this epidemic.

The overall consensus was to expand GIPA to include those most affected as well as PLHA. With this in mind, please be aware that throughout this report, GIPA will refer to the **Greater Involvement of People Living with or Affected by HIV/AIDS**.

[1] Declaration of the Paris AIDS Summit (Section IV, Paragraph 1) available at http://www.unaids.org/whatsnew/conferences/summit/index.html

SUMMARY OF THE NAIROBI CONSULTATION ON GIPA

Format and Purpose of Consultation

The Consultation on the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA), held in Nairobi, Kenya 28th of February - 1st of March 2000, was designed to bring together a cross section of individuals, representatives of community groups and UNAIDS cosponsors to obtain insight into challenges and opportunities related to UNAIDS commitment to enhance the GIPA initiative. This consultation, supported by UNAIDS and co-ordinated by the Regional AIDS Training Network (RATN), had a global perspective with an emphasis on Africa.

The Consultation attracted nearly thirty participants (see attached list - annex 2) representing some twenty countries spanning all regions of the globe. This list also provides a base upon which a resource network of individuals able to provide insight on GIPA can be built.

The approach used by the facilitators (Jens Van Roey, Milly Katana, Moustapha Gueye and Josef Scheich) was intended to ensure participation by all individuals. Participants listened to formal presentations designed to enhance the learning of experiences from the field. Plenary discussions and small group work were also held and designed to help in consensus building.

The meeting was opened by Warren NAAMARA, UNAIDS Country Programme Advisor in Kenya. In his speech he stressed the need to involve people living with and affected by HIV/AIDS and hoped that the meeting would reflect on obstacles to involvement and take them into consideration when designing GIPA-focused work plans.

The following pages outline the four meeting objectives, the related discussions that ensued and the ultimate session outcome for each respective objective. The specific objectives were as follows:

- Objective 1 - To generate an operational understanding of the GIPA principle.
- Objective 2 - To share experiences of various mechanisms of enhancing GIPA.
- Objective 3 - To explore opportunities and obstacles related to the implementation of GIPA activities.
- Objective 4 - To explore future perspectives and mechanisms for enhancing GIPA.

Objectives and Outcomes

OBJECTIVE 1 - TO GENERATE AN OPERATIONAL UNDERSTANDING OF THE GIPA PRINCIPLE

The aim of this session was to discuss the issues surrounding the underlying meaning of GIPA and to achieve consensus on a working definition for the purpose of implementation of GIPA.

It was generally agreed that the operational definition of GIPA should focus primarily on infected persons but should not exclude those most affected. There is a need for specific focus on infected persons in order to avoid dilution of the principle which would result from attempting to include everybody. Nonetheless, there is a role for those most affected by the disease which will enhance GIPA initiatives, rather than detract from its impact.

Clear arguments supporting the focus to remain on PLHA stem from the fundamental fact that the experience of living with HIV is not something that can ever be fully understood by those who are not infected, no matter how close, unless they too have endured the same experience.

Furthermore, while those most closely affected share many of the same burdens, such as stigma and social discrimination, they are rarely subjected to the same level of legal discrimination (e.g. immigration laws prohibiting free travel of PLHA). They do, of course, endure the consequences of such discrimination, particularly the spouses, partners, children, parents and close relatives of the PLHA.

It was also discussed, at length, that the current number of HIV+ individuals willing and able to participate fully in the initiatives borne from GIPA remains extremely low. In this vein it is also critical to acknowledge that the most successful occurrence of GIPA, on an individual level, is often buffered by acceptance and support of family and close relatives to become meaningfully involved. Paradoxically, for those suffering ostracism from their families, involvement can often provide a renewed sense of support from others involved in the fight against HIV/AIDS.

With this in mind, it was concurrently agreed that the epidemic is advancing far more rapidly than society and we can not afford to limit ourselves to the exclusivity of PLHA when those most affected have a critical role to play in fighting for the rights and needs of PLHA and all that that implies.

Finally, it was acknowledged that while the operational definition of GIPA outlined in this report is to be used, it is understood that GIPA shall always be adjusted to given national, environmental, political and community contextual factors.

OUTCOME - OBJECTIVE 1:

A consensus was reached that the operational definition of GIPA is to focus primarily on those infected without excluding those most affected (spouses, partners, children, parents, etc.).

OBJECTIVE 2 - TO SHARE EXPERIENCES OF VARIOUS MECHANISMS OF ENHANCING GIPA

The thrust of this session was to get an overall sense of what is currently occurring in terms of GIPA initiatives in country and beyond. Representatives of several ongoing programmes presented their experiences regarding enhancing GIPA. Discussions covered issues of successful GIPA implementation as well as constraints facing further GIPA actualisation.

Some of the successes of GIPA initiatives included increased HIV/AIDS awareness and PLHA involvement at many levels. At the individual level, the actualisation of GIPA has increased success rates of support groups and networks of PLHA. At the institutional level, GIPA has increased peer-guided care and prevention efforts ranging from policy formulation to activity implementation including Income Generating Activities. At national levels we see increased level of Government and donor support both in terms of budgetary allocations and actionable outputs. This extends as far as governmental negotiations towards minimising costs for Anti-Retrovirals (ARVs). At national, regional and even international levels we have also seen a positive increase in media coverage of the pandemic as PLHA come forward and demystify the experience of living with HIV or AIDS.

Distinct challenges were also acknowledged as recurring in the efforts to step up GIPA. The largest obstacle remains the stigma so often experienced by those who disclose their sero-status in the attempt to raise the visibility of PLHA. The fear of disclosure often silences potential new voices, thus leaving a situation where very few PLHA are doing an enormous amount of work. Despite their dedication, these people are often with little support and certainly have no greater assurance of quality of care or access to treatment than any other individual living with the virus. These individuals, while definitely appreciated by many, are rarely given due praise for their work and sacrifices - the minimum one needs to keep going-. Additionally, we find that the needs for effective GIPA is not frequently enough matched to the capacity of individuals, thus requiring skills building and re-skilling of PLHA so as to be most effective in their new roles, be that peer counselling or policy making. Having HIV is an experience, not a skill. Rather, our skills are built around living with the virus in a positive and productive way. Additional abilities must be developed to cope with common stigma and discrimination that often accompanies deeper involvement of PLHA and those most affected by the epidemic.

OUTCOME - OBJECTIVE 2:

Experiences of ongoing GIPA initiatives were shared and discussed to begin mapping out global experiences of enhancing GIPA. From this session and pursuant examination of constraints of current projects, the conclusion was reached that despite obstacles of implementing GIPA, the initiatives do have a meaningful impact and must be continued and expanded.

OBJECTIVE 3 - TO EXPLORE OPPORTUNITIES AND OBSTACLES RELATED TO THE IMPLEMENTATION OF GIPA ACTIVITIES

Following the session on Objective 2 which gave an overview of current GIPA successes and restraints, the group decided that the session on Objective 3 would primarily address the issue of stigma and discrimination, as this was seen to be the main obstacle to GIPA implementation. This is an issue that needs clarification before viable opportunities for GIPA implementation can be approached.

Discussion focused initially on the manifestations of stigma. They were described by small working groups as occurring in the four main areas outlined below.

Self-stigmatisation was described as avoidance of people, withdrawal, depression and self-hatred. It was also explained that this is often expressed as low self-esteem and frequently involves receiving and playing out expectations to play the role of an ill person or of becoming the "victim" which is not only self-defeating but can have a negative impact on one's mental well-being and in turn on ones physical health.

Stigma from the Health Care Sector was characterised as apathy in medical structures, judgementalism from counsellors and medical staff, compulsory or involuntary disclosure and even excessive sympathy.

Representation and communication were identified as potential mechanisms of continued stigma due to careless language and unclear terminology used by the media, social leaders and society in general. Stigma also arises from misrepresentation of PLHA as people who are dying from rather than living with a virus, as well as misconceptions about the behaviour of PLHA, particularly sexual behaviour. Misinformation, clearly, is a key source of unwarranted stigma as people often have wrong information as to prevention of HIV and routes of transmission. Finally, tokenism was considered as an additional source of stigma for PLHA, occurring when individuals are utilised for the needs and aims of other people or organisations.

Social and work environments were also discussed as potential obstacles to the implementation of GIPA as hostility, violence, silence and denial about HIV/AIDS only leads to exclusion of PLHA. This can occur from institutions such as work or housing or even from programmes such as insurance or support systems.

Having identified manifestations of stigma, the meeting then discussed and agreed on *means to address these* at the individual, institutional, community and national levels as related to the implementation of GIPA and beyond. Many of these mechanisms are crosscutting; they apply equally to all four levels. Examples of these include provision of Information, Education and Communication (IEC), identifying and supporting appropriate role models and giving them visibility through use of the media, training sessions/workshops for people involved (health professionals, families, community leaders and politicians), PLHA activism and assertion, and development of indicators for stigma reduction. At specific levels of activity, additional suggestions were made and are outline below.

Individual Level: Effective means of addressing stigma at this level were highlighted as encouraging development and use of support groups, psychosocial support and peer support for PLHA as well as providing other opportunities for confronting individuals fears, promoting honesty in relationships and providing knowledge about ones own body and the virus that one is living with. Promotion of Voluntary Counselling and Testing (VCT) and the use of role modelling were also discussed along with the idea of integrating being open about HIV/AIDS with ones other regular duties. Beyond these ideas

it was discussed that the alleviation of impact through income generating projects is another excellent mechanism for rebuilding ones confidence and diminishing stigma as the PLHA are then viewed as autonomous productive individuals rather than sickly or needy victims.

Institutional Level: At this level we need to identify institutional indicators for stigma and stigma reduction and in turn generate regulations and professional codes for appropriate professional conduct. This would require participation and support of management level workers and would necessitate ensuring space for discussion of HIV/AIDS in workplaces as well as supporting PLHA to choose to be open about their HIV status or not. It also infers enabling work adaptations during periods of illness as well as endorsing material, medical and psychosocial support for those who decide to be "open" so that they do not face ostracism from co-workers or loss of services available to other employees.

Community Level: At this level there must be facilitation of expanded community responses including the involvement of celebrities and engagement of religious and political leaders as well as developing solidarity in community work. Additionally, there is a need to develop mechanisms to both educate community on rights and responsibilities in respect to HIV/AIDS as well as to address violations of rights of PLHA and those affected.

National Level: At this level (and beyond) there is a need for enhanced visibility of PLHA at national events. Also, we need expanded awareness campaigns, generated with the involvement of Human Rights organisations, on the rights of PLHA. There must also be greater provision of appropriate legislation and policies to protect and promote the Human Rights of PLHA.

OUTCOME - OBJECTIVE 3

Following the in depth discussion surrounding the opportunities and obstacles for implementing GIPA it was agreed upon that the greatest obstacle was the stigma experienced by those living with HIV and particularly those PLHA who had, for whatever reason, disclosed their status. It was therefore implied that the opportunities for GIPA will only present themselves in an environment where stigma has been reduced and an overall acceptance of PLHA prevails.

OBJECTIVE 4 - TO EXPLORE FUTURE PERSPECTIVES AND MECHANISMS FOR ENHANCING GIPA

In order for GIPA to take root, the participants identified the following five key strategic areas to be developed and acted upon: Stigma and Discrimination; Communication and Information Sharing; GIPA at Institutional and Policy Levels; Empowerment of PLHA and Groups of PLHA; and Advocacy. Each area below was thoroughly discussed and then matched with objectives, activities and responsible entities.

STIGMA AND DISCRIMINATION

OBJECTIVE *- To reduce the manifestations of stigma and discrimination.*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Educational programmes for the media, political leaders and schools	Groups of PLHA, Governments, NACPs, NGOs, CBOs, community and family
Capacity building and enhancement of skills of PLHA in public speaking, empowerment counselling, raising self-esteem etc...	Groups & Networks of PLHA, NACPs, UNAIDS and its Co-Sponsors
Promotion of Voluntary Counselling and Testing (VCT)	NACPs, NGOs, CBOs, UN Agencies, Private sector, Hospitals, Groups of PLHA and Religious Organisations
Advocate for laws and policies to protect the rights of PLHA and affected persons	Networks for law and advocacy, human rights groups, PLHA activists, UNAIDS Technical Team on Stigma, Discrimination and Denial (SDD)
Role modelling such as the Ambassadors of Hope Project	Groups and Associations of PLHA
Documentation of manifestations of stigma	Groups and Associations of PLHA, UNAIDS and its Co-Sponsors, local NGOs and the Media

COMMUNICATION AND INFORMATION SHARING

OBJECTIVE *- To broaden the message of GIPA and increase the number of diverse partners through outreach*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Putting a new Team Approach to UNAIDS Public Relations and Communication programmes that includes GIPA	UNAIDS and networks of PLHA

OBJECTIVE *- To learn from a variety of partners (local Community Based experiences) and organisations on how GIPA adds value to projects*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Publish and distribute best practice models that show the expressions of GIPA	UNAIDS (Geneva and Intercountry Teams), its Co-Sponsors, bilaterals

OBJECTIVE *- To communicate the positive patterns of expression through which HIV/AIDS can influence public policies and government engagement.*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Regular information exchange from groups of PLHA, CBOs and Networks through multi-media including local conversation	CBOs, Networks and Local Community

OBJECTIVE *- To foster ownership of information exchange at the CBO and national network level*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Identify and use existing dissemination channels to enhance the role of GIPA in the global response	UNAIDS, governments, NGOs and PLHA

OBJECTIVE *- To help build the capacity to learn from the experience of GIPA so as to avoid one-off activities that provide little or no lasting impact. This applies to all levels from local to international.*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Develop marketing/advocacy materials that urge "buy-ins" to GIPA through affirming contributions by PLHA	UNAIDS, PLHA
Build partnerships with private media to highlight contributions of PLHA - e.g. person/organisation of the month	UNAIDS (Geneva and Intercountry Teams), PLHA and the Media

GIPA AT INSTITUTIONAL AND POLICY LEVELS

OBJECTIVE *- Raise awareness about HIV and AIDS and the GIPA Initiative*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Information sessions (at national levels)	Groups of PLHA and NGOs
UNAIDS PCB (representation at the programme co-ordination board)	NGOs, Groups of PLHA and the PCB-NGO/PLHA Delegation
Ambassadors of Hope - continuation and expansion of project	Continental Networks (e.g. NAP+), PLHA and NGOs
Advocacy session with focal points and NGOs	Groups and Associations of PLHA
Regularly invite UNAIDS staff and Co-Sponsors to visit projects	Groups and Associations of PLHA
Advocacy letters to the highest levels (Heads of States)	Groups and Associations of PLHA
Information collection on discrimination	Organisations of PLHA

OBJECTIVE *- To promote the adoption and implementation of policies and laws that protect the rights of PLHA*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Information and advocacy sessions including Group Discussions, Story Telling, Testimony (and documentation of people's experiences) as well as Press Releases	Politicians, Business Leaders, Groups of PLHA, Human Rights Groups

OBJECTIVE *- To increase mobilisation of resources*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Fund-raising events and requests and the eventual establishment of Community Foundations	NAPs, Business leaders, Groups and Associations of PLHA, UNAIDS and its Co-Sponsors and Networks of PLHA

EMPOWERMENT OF PLHA AND GROUPS OF PLHA

OBJECTIVE *- To understand one's own health and treatment information.*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Newsletters, workshops, hotlines and internet information sharing	NGOs, Groups of PLHA

OBJECTIVE *- Become a partner in one's own healthcare*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Train healthcare professionals to better inform and educate their clients	PLHA and groups of PLHA

OBJECTIVE *- Skills development and technical expertise*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Training, mentoring and sharing best practices, evaluation and monitoring	PLHA Organisations, Doctors, Scientific and Professional Associations

OBJECTIVE *- Personal and Group Development*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Personal and Organisational Training Development	Donors, Professional Associations, NGOs

OBJECTIVE *- Representation at board levels*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Lobby Organisations for inclusion - show examples of successes (e.g. UNAIDS' PCB)	NGOs and Groups of PLHA

OBJECTIVE *- Acceptance of shared responsibility for training and development*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Show value of PLHA participation - NO TOKENISM	Groups of PLHA and bodies and boards where they are placed

ADVOCACY

OBJECTIVE *- Access to care and treatment including lower cost treatments, better research, vaccine development and higher standards of care*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Lobby Pharmaceutical companies for Compulsory licensing, negotiation of settlements, to set standards of marketing practices and to review corruption costs and import duties	Treatment Groups, Networks of PLHA, Governments

OBJECTIVE *- - Implementation of anti-discriminatory legislation covering employment and travel insurance*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Review existing legislation, draft and lobby for new legislation and set up access to legal advice clinics	Groups of PLHA, legal Associations, Legislators, Local PLHA Group appropriately trained in legislation and legal issues

OBJECTIVE *- Ability to hold ìactorsî responsible for commitment*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Review of government budgets and actions	Groups of PLHA

OBJECTIVE *- Increased Voluntary Counselling and Testing which may lead to prevention of mother-to-child transmission of HIV by allowing couples to make better informed decisions*	
ACTIVITIES	***RESPONSIBLE ENTITIES***
Publicise standards to patients and healthcare professionals with monitoring of implementation	Groups of PLHA, Professional associations of health care providers

OUTCOME - OBJECTIVE 4:

The outcome of this objective was the identification and prioritisation of key areas. The next step will be the development of a plan of action for implementation of related activities by all involved entities.

Presentation Summaries

THE EVOLUTION OF GIPA - THE ROAD TO NAIROBI FROM DENVER VIA PARIS (JOSEF SCHEICH)

This presentation discussed the evolution of the movement which, many consider, gave birth to what is now GIPA. In particular it described the 1983 Denver Principles which are the first documented words of PLHA seeking greater respect and involvement. The exact principles are as follows:

- A refusal to be "victims".
- A request for support from all people.
- A plea against stigma and discrimination.
- A call to arms of all people with HIV to choose:
    - ⇒ To be involved at all levels of decision-making.
    - ⇒ To be included in all AIDS Forums.
    - ⇒ To be responsible for their own sexual health and to inform their partners of their HIV status.

The Denver Principles further to identified and demanded the following five human rights:

- A full and satisfying sexual and emotional life.
- Quality medical treatment and social service provision.
- Full explanations of medical procedures and risks and the right to choose or refuse treatment.
- Privacy and confidentiality of medical records and disclosure.
- To die and live in dignity.

The activism of the following years was briefly highlighted. He then discussed the evolution of the 1994 Paris AIDS Summit, the consultations that led to the drafting of the Paris AIDS Declaration and the consultations that followed regarding the GIPA Initiative. In summary, he explained that five years on from the Paris AIDS Summit no additional governments have signed on to the Declaration nor has a mechanism been established for monitoring GIPA related activities among the signatories. Neither has a concrete work plan been developed to implement the principle aside from pilot projects. As he explained, this does not rule out ultimate success as meaningful GIPA will not come overnight - it is an ongoing process. All of us, and in particular PLHA, have a responsibility to make it work. We must move from concept to reality and operationalise it. In closing he stated that maybe it ís time to look back to our grass roots and regain our activism.

OPERATIONAL DEFINITIONS (NOERINE KALEEBA - UNAIDS AND JENS VAN ROEY - TIBOTEC)

This presentation emphasised that the lead in GIPA must be assumed by PLHA so as to avoid dilution of the initiative. Nonetheless, those most affected must also be included - with clearly defined boundaries and roles - and allowed to have an impact through GIPA initiatives as those closest to PLHA are often equally affected by the epidemic - albeit in different ways. We must neither forget that support of those affected often gives strength to PLHA to be "open" about their status and so their help must be recognised. If we are to put a face to the epidemic we can not select only a part of the image, all should be included. It was discussed that "Hope" alone is motivating involvement for many although good role models are also crucial as is technical support. Social and legal discrimination must be recognised and to this end, a few questions were raised: is the person who does not disclose a "victim of society"? What happens after disclosure? It is apparent that a great deal still needs to be more clearly defined to advance with GIPA initiatives. We must not procrastinate and need to cast our nets as wide as possible to ensure the success of GIPA by including those infected and affected at local, national, regional and global levels.

THE WEDNESDAY FRIENDS CLUB UNDER THE THAI RED CROSS AIDS RESEARCH CENTRE

The Club was founded in 1991 by PLHA seeking treatment at Chulalongkom Hospital. In the beginning the members met every Tuesday morning but later decided to meet every third Wednesday of each month making a support group to reach out to others living with HIV/AIDS. The group then became called the "Wednesday Friends Club"

Main Objectives:

- To provide members with information and mutual support.
- To promote understanding and positive attitudes within society towards PLHA.
- To co-operate with organisation working towards the prevention of HIV infection.

Club Activities include:

- HIV-Phone.
- Individual and Group Counselling.
- Educational Outreach, Volunteer Program and Home Visitation.
- Red Ribbon Newsletter, Guest Speakers, Sports & Recreation, Meditation and Income Generating Activities.
- Free Lunch and Free Haircut Programmes.

Additional External Activities at the following Centres Include:

- *Welfare Unit of Chulalongkom Hospital*: Individual and Group Support (Counselling) and HIV-Phone.
- *Thai Red Cross AIDS Research Centre*: Individual Counselling; HIV-Phone; AIDS Care Phone and Capacity Building (management skills, public speaking etc.) for PLHA-Project planning.
- *Health in Home Instruction, Central Bureau*: Home Care Training for Home Visitation.

INSIGHTS FROM THE INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV/AIDS (ICW)

The ICW is the only international network run for and by HIV+ women. ICW was founded in 1992 at the 8th International AIDS Conference, held in Amsterdam, by a group of HIV+ women from many countries. Today, membership - which is free and open to all HIV+ women and to organisations - is estimated at around 2,000 members from all regions of the world.

Objectives include:

To reduce isolation of positive women through information exchange, self-help, recognition of Human Rights and setting up local support networks.

Current Projects include:

- ICW Quarterly Newsletter.
- Positive Women Voices and Choices Project.
- Indian Regional Training for positive women (planned for end of year 2000).

Achievements include:

- Increased visibility - and audibility - of HIV+ women at all levels.
- Co-organisers of international conferences (with GNP+).
- Launch of the Positive Woman's Survival Kit.

Challenges include:

- Stigma in many countries remains such that women cannot come out about their status.
- Work load is too high and area of outreach is extremely vast for low number of paid staff leaving much work to be done by unpaid volunteers. Many of the founders have resigned due to burn out.
- Lack of funding.

INSIGHTS FROM THE GLOBAL NETWORK OF PEOPLE LIVING WITH HIV/AIDS (GNP+)

This presentation discussed workshops for Building a Global Advocacy Agenda occurring at the Ninth International Conference for PLHA, held in Warsaw, Poland in 1999. One of the outcomes of the meeting was a group discussion and recommendations on the promotion of GIPA, as is summarised.

The groups saw three major issues concerning the GIPA initiatives:

- That PLHA are used as tokens and not included as equal partners in the initiative, their HIV status being of primary concern and with built-in institutional limitations restricting use of their expertise.
- The lack of continuous and ongoing follow-up regarding implementation of GIPA.
- The need for HIV to be seen as a problem which affects a number of different sectors of society and that interventions must also include all affected and concerned sectors.

The following action plans were recommended:

- "Report Cards" should be issued by GNP+/ICW concerning the implementation of GIPA initiatives targeting National Governments, NACPs, National Health Ministries, Development Assistance Organisations, UNAIDS and its co-sponsors, the private sector (business), National PLHA Networks and GNP+ and ICW themselves.
- "Report Cards" should include a number of indicators including those available from external sources such as UNDP World Development Report, UNAIDS and Amnesty International as well as those developed and collected by GNP+ and ICW.
- The "Report Cards" should include a self-report mechanism which force target recipients to first rate themselves and which will be compared to the available indicators and information from other sources.
- The "Report Cards" should include aspects to promote and measure the technical competence of the HIV+ participants in GIPA initiatives.
- GNP+ and ICW would use existing regional and local networks to implement the "Report Card" scheme.
- GNP+ and ICW would facilitate and promote discussions on what is an acceptable partnership concerning GIPA.

THE SALVATION ARMY, KENYA

This presentation discussed, at length, the importance of faith in the work of the Salvation Army in Kenya. Every act of care, it was explained, involves physical and spiritual dimensions - sometimes spoken, sometimes felt and sometimes silent. It was presented that a higher power is calling the modern man today to rebuild communities and families through pastoral care and counselling. Through this vision of the power of helping persons and families affected by HIV/AIDS, they began progressive community counselling as well as the start of Home Visits.

Kibera Anti-AIDS project was started to cater for the community as a whole to support families and PLHA, orphans and to do youth sensitisation. The Community meets once per week and home visitation and home care is done on a regular basis. They have reached out to many communities working with HIV and AIDS through Public Awareness, Training and Counselling of PLHA, Youth Group formation and mobilisation and motivation of the community.

In closing the presenter urged everyone to give of themselves fully to their work on HIV/AIDS. However big or small our actions, the message is not in vain but a living message of fighting HIV/AIDS because with faith we can face tomorrow.

NACWOLA

The goal of NACWOLA is to improve the situation of HIV+ women living in Uganda.

Objectives:

- To fight stigma and abuse of HIV+ women in Uganda.
- To access HIV/AIDS information to reduce fear and isolation among HIV+ women.
- To empower HIV+ women economically to reduce vulnerability and dependency.
- To unite all HIV+ women in the fight against AIDS.

Achievements include:

- Accepting our personal responsibility as PLHA to see change occur.
- Contribution to the reduction of fear of AIDS in our community.
- Raising the voice of PLHA - We are heard and respected.
- We have followed the role model of ICW and serve as a model for others.

Enabling Factors include:

- Political will by our government and Self-determination of individuals.
- Working in partnership with other organisations (TASO, Save the Children, etc.).

Challenges include:

- Stigma, especially among the professional and highly skilled PLHA.
- Provocation for members who go public.
- Burn-out and lack of compensation for voluntary work.
- Political leaders lag behind and pay "lip service" to the struggle.

Recommendations:

- Involvement of political leaders in a more meaningful way.
- Documentation of best practices of PLHA involvement.
- Skills building (training) for PLHA in communication skills.
- Recognition and appreciation of the invaluable work of PLHA.

ANSS BURUNDI

In 1993, the "Association Nationale des Séropositifs et Sidéens" (ANSS) was created with the aim of lifting the myth around HIV/AIDS. A few PLHA came forward and publicly acknowledged their sero-status in an unprecedented event nation-wide. It was risky as no one could predict people's reaction but it was worth it and we did it. Fortunately, the reaction in Burundi was positive and prompted many people to seek counselling and testing. For those already positive, it was a relief to find a safe space to talk freely and receive emotional and social support. Over time, the group has changed its name to the "Association Nationale de Soutien aux Séropositifs et aux Sidéens" so as to expand membership to both those most affected by the disease as well as those not yet ready to disclose their status, as well as other persons.

With the support of a French NGO, ANSS has opened a care and support centre called "TURIHO" which in Kirundi, the Burundian national language means "We Are Alive". The main activities are:

- Prevention activities and the promotion of VCT.
- Medical care and psycho-social support for PLHA (including home based care) food aid and nutritional support.

Given the inherent limitations of volunteerism, the Centre has chosen to invest in permanent and paid staff to allow provision high quality and quantity services to its members. It is worth mentioning that the Centre is managed by infected and affected people who are recruited on the basis of their involvement in the work of ANSS.

LUMIÈRE ACTION - COTE D'IVOIRE

Lumière Action was created in 1994 by students as a non-profit making organisation with the main goal of action for a stronger response to HIV/AIDS. The Association accepts membership of anyone who wants to join.

Objectives:

- To provide psychosocial support to members.
- Work against discrimination and stigma.
- Advocate for treatment for all infected people.
- Start groups in other areas of Côte d'Ivoire.

Major activities include:

- Hot-line.
- Home and hospital visits.
- Pre- and post-test counselling.
- Prevention and control activities in high schools.
- Medical and educational advice to PLHA.
- Education on prevention of mother-to-child transmission of HIV.

The Côte d'Ivoire Access to Treatment Campaign was also presented.

Objectives:

- To ensure procurement of ARVs for PLHA.
- Needs assessment of PLHA.
- Reduce AIDS related deaths.
- Home visits for advocacy purposes.

Results of the project include:

- 367 people have benefited out of which 9 have died and 83 are lost to follow-up.
- People working with support groups can better understand the needs of PLHA.
- Counselling demands are increasing as the use of ARVs requires close follow-up.

INSIGHTS FROM THE NETWORK OF AFRICAN PLHA (NAP+)

The NAP+ began in 1993 by PLHA in Africa. The structure includes a Governing Board, a Secretariat in Nairobi and two support offices in Lusaka and Abidjan. The Board consists of 10 representatives from all sub-regions of Africa and meets regularly to pass policies and monitor progress on activities.

Main Activities of NAP+ include:

- Linkages of PLHA in Africa.
- Providing a formal forum for PLHA in Africa.
- The Ambassadors of Hope Programme which focuses on role models of PLHA.

Impact of the Ambassadors of Hope Programme:

- Increase in networks of PLHA.
- Increase in support groups.
- Greater involvement of PLHA in some countries.
- In some countries, involvement has increased to direct government support for groups.
- Better formulation of policies that are sensitive to the needs of PLHA.
- Increased capacity of PLHA networks.
- Better media coverage, especially in places like Nigeria, that aims at empowering and not disempowering PLHA.

UNV Pilot Projects - Malawi, Zambia and the GIPA Pilot Project - South Africa

The UNV Pilot Projects are a collaboration among four partners, NAP+, UNV, UNDP and UNAIDS which focus on giving HIV/AIDS a human face and voice. In Malawi and Zambia, the project utilised the UNV volunteer modality to enhance the work of people who were already open about their sero-status by placing volunteers at various levels of the national response. South Africa opted to use the "field worker" modality placing PLHA within the private sector as host institutions.

In Malawi and Zambia the objectives were to:

- Provide a structure and atmosphere in which PLHA contributions could be supported.
- Provide training and skills provision to PLHA who were already working.
- Provide recognition for meaningful involvement of PLHA.
- Ensure that the work of PLHA could fit into the national HIV/AIDS responses.

In South Africa the objectives were:

- Greater involvement of PLHA in the development of work-based policies and programmes.
- Increased visibility and understanding of the HIV/AIDS epidemic within organisations.
- Establishment of networks and support structures for PLHA and associations.

The ultimate success of these projects has been extraordinary. The Projects have demonstrated that PLHA and their involvement engender a dialogue within communities about how they can live with the epidemic and that PLHA are part of the solution rather than the cause of the problem.

Stigma, Discrimination and Denial (SDD) - A Time To Act (David Miller - UNAIDS)

This presentation discussed a prior meeting on SDD, its background, aims and outcomes. Some of the most telling information was on overcoming SDD in various settings, as highlighted below.

Overcoming SDD in Family/Community:

- Requires outreach activities that actively demonstrate close contact without infection.
- Demonstrating by example about basics - e.g. washing, waste disposal, etc.
- Education seminars, support group formation.
- Mainstreaming HIV experience.

Overcoming SDD in the Workplace:

- Targeting specific instances of SDD.
- Awareness-raising and education workshops.
- Policy formation in workplaces.

Overcoming SDD in Health Services:

- Accurate HIV/AIDS information - e.g. transmission, prevention, local services, etc.
- Strengthening care options.
- GIPA in regime-setting.

Overcoming SDD through the Media:

- Participation of respected leaders.
- Advertising positive values linked to HIV.
- Publicising stories of PLHA - personalising the epidemic.

Overall Recommendations:

- Encourage and nurture GIPA.
- Address the whole continuum of care and support.

BASIC REQUIREMENTS FOR MEANINGFUL INVOLVEMENT - GIPA (RON MACINNIS)

Conditions for Safe and Effective Involvement:

- *Individual Level*: it has to be a personal initiative to become involved
- *Organisational Level*: certain pre-conditions for safe involvement include: Sensitivity Training for Colleagues, Information about opportunities for GIPA, Appropriate Training for the tasks to be undertaken and Optimal use of existing skills
- *Institutional Level*: There must be laws for protection of PLHA who become involved.

Objectives for becoming involved:

- Use of the experience of PLHA or affected persons in the response to the epidemic.
- Give a human face and voice to the epidemic.
- Involvement at all levels, in all sectors and in all roles.

Greater involvement can:

- Reduce stigma and discrimination at all levels.
- Build on direct experience - boost morale, team building, planning of activities.
- Increase acceptance by peers.

Key issues in involvement:

- Prior to disclosure of sero-status, one needs a personal counselling structure, prior preparation and skills building on going public, personal empowerment training and to address the fear of rejection by ones own community, as well as personal clarification of *why* one is getting involved.
- Burn-Out: one needs strong support structures in place to deal with potential Burn Out.

Findings from the field have shown:

- Motivations for involvement are because of reasons of access to care.
- Obstacles to involvement include: sero-status is often unknown, fear of stigmatisation and discrimination, few formal referral systems to organisations, exhausting nature of voluntary work, and lack of training opportunities that could enhance meaningful involvement.

THE INTERNATIONAL PARTNERSHIP AGAINST AIDS IN AFRICA - IPAA (UNAIDS)

The IPAA is a *coalition of actors* including, African governments, African and International Civil Society, the United Nations (UN), Donors, Foundations, Private and Corporate Sectors working together at all levels to achieve a common vision, common goals and objectives based on mutually agreed principles, and key milestones. The vision of the IPAA is that within the next decade, African nations will be implementing larger-scale sustained and more effective national responses through: Promotion and protection of human rights; Reduction of new HIV infections; Provision of a continuum of care for those infected and affected by HIV/AIDS and Mobilisation of Communities, NGOs, the private sector and individuals to counteract the negative impact of the HIV/AIDS epidemic in Africa.

Proposed Principles include:

- African ownership of the Partnership at all levels: country and community priorities to drive the action and implementation plans will be based on local priorities and contexts.
- Active involvement of people living with and affected by HIV/AIDS in setting the parameters, designing implementation and evaluation of the Partnership.
- Respect, protection and fulfilment of human rights, compassion and active opposition to all forms of stigma and exclusion of PLHA.

The Proposed Goal of the IPAA:

The overall goal is to curtail the spread of HIV, sharply reduce the impact of AIDS on human suffering and on the development of human, social and economic capital in Africa.

PLAN OF ACTION

The overall Plan of Action is outlined in the section on Objective 4. Beyond these key strategic areas of Stigma and Discrimination; Communication and Information Sharing; GIPA at Institutional and Policy Levels; Empowerment of PLHA and Groups of PLHA and Advocacy, a few additional areas to focus action on are listed below.

- Survival: The strong will to survive leads to people being involved.
- Success: Successes that have been seen on the ground encourage people to go further.
- Self-determination.
- Networking through the internet and other electronic means.
- Donors have the power to influence policy and programmes and they should try to impact positively on national level programmes through encouragement of GIPA.
- The opportunity to address the environment for safe disclosure through GIPA must not be missed.
- UNAIDS, through GIPA, should include PLHA in high level press briefings and meetings with Presidents and other national level leaders.

Beyond these areas of Action, UNAIDS, through its GIPA Focal Person and other designated staff, both in the Secretariat and in the field, will continue to expand understanding and implementation of GIPA. As appropriate, future consultations may be organised, however, the main thrust of UNAIDS' work will be to enhance GIPA from the grass roots level up, in operational ways, rather than theoretical.

It is envisioned that Best Practice Documents be generated in areas relating specifically to GIPA, including UNAIDS' own experiences of GIPA through staffing, advisory boards, consultations and programme co-ordination and the impact of participation of PLHA and persons affected by HIV/AIDS.

Community pressure is also remounting as regards the Paris AIDS Declaration and the hope that not only will the current signatory countries be held accountable for their role on increasing GIPA (or lack of) but that additional nation-states will sign on and begin to assume responsibility for implementation of GIPA.

In short, the Plan of Action is still in development but the commitment of UNAIDS to enhance GIPA is real. On-going dialogue and activities will increase and expand at every possible opportunity through, for example, the International Partnership Against AIDS in Africa, as well as other projects, to ensure participation of PLHA and those affected by the epidemic in all regions and at all levels.

CONCLUSION

In conclusion, this three day consultation - while incredibly challenging - was extremely fruitful and beneficial to the work of UNAIDS and all those who attended. We hope that this report will provide some insight into the current issues surrounding GIPA and that they will guide readers in further implementation of initiatives.

We wish to thank all of those who participated and, especially, those who worked hard to prepare and organise the meeting as well as see to follow-up and appropriate recording of the meeting to allow us to produce this report.

If you have documented successes of GIPA, constructive suggestions for expansion of initiatives or any further measurable experience that you feel would be useful to UNAIDS work on GIPA, we would be grateful to hear from you. Please contact us at the following co-ordinates:

Salvator NIYONZIMA, Focal Person GIPA
Department of Policy, Strategy and Research
20, avenue Appia
CH-1211 Geneva 27 - Switzerland
Tel: (+41 22) 791 4448
Fax: (+41 22) 791 4741
E-mail: niyonzimas@unaids.org
Internet: http://www.unaids.org

MONDAY FEB. 28, 2000

Facilitator: Jens VAN ROEY

8.30 : Introductory session (introduction of participants; discussion of objectives).
9.30 : Opening
10:00 : Health break
10:30 : The Evolution of GIPA (presentation by Josef SCHEICH)
11:00 : Operational definitions (presentation by N. KALEEBA and Dr J. VAN ROEY)
12:30 : Lunch break
14:00 : Implementation models of GIPA in place so far (presentations)
The Wednesday Friends Club (S. Umasa)
Insights from ICW, GNP, The Salvation Army, NACWOLA
15.45: Small group work: Challenges identified from above models
16.15: Health break
16.30: Plenary session

TUESDAY FEB. 29, 2000

Facilitator: Milly KATANA

9:00 : Implementation models of GIPA in place so far (continued)
ANSS - Burundi
Lumière Action - Côte d'Ivoire
The Ambassadors Missions (NAP)
UNV, UNDP & UNAIDS: GIPA pilot projects
10:00 : Health break
10:30 : Small group work: How can we address stigma in order to enhance GIPA?
(Individual, Institutional, Community and National Level)
11:30 : Plenary session: reports from group work
The Challenges of Stigma (DAVID MILLER)
12:30 : Lunch break
14:00 : Introduction to group work (N. KALEEBA AND S. NIYONZIMA)
Topics: Basic requirements for meaningful involvement.
What needs to be done to yield greater involvement?
15:30 : Health Break
16:00 : Reports from group work
Basic requirements for meaningful involvement (RON MACINNIS)

WEDNESDAY, MARCH 1ST, 2000

Facilitator: Josef SCHEICH

9:00 : Reflection session
9:15 : Strategic alliances for GIPA: roles and responsibilities of CBOs, NGOs, governments, private sector (Small group work) M. GUEYE AND M. KATANA
10:00 : Health break
10:30 : Reports from group
11:00 : Building GIPA within the IPAA (introduction and group work)
12:30 : Lunch break
14:00 : Plenary (group reports)
14:45 : Plenary session
Broad framework for GIPA (S. NIYONZIMA)
15:45 : Health break
16:00 : Summary (S. NIYONZIMA)
Informal evaluation
16.45 : Closing

ANNEX 2 - PARTICIPANTS LIST

NAME	AFFILIATE & COUNTRY	CONTACT DATA
JENS VAN ROEY	TIBOTEC - BELGIUM	General de Wittelaan L-11 B3 2800 Mechelen BELGIUM Tel: 32 51 69 32 42 E-mail: Jens.van.roey@pandora.be
MICHAEL D. FOX	CARIBBEAN REGIONAL NETWORK OF PLHA - BERMUDA	Suite # 172 48 Parlaville Road Hamilton HM 11 BERMUDA Tel: 441 234 4319 Fax: 441 296 1180 E-mail: mdfox@ibl.bm
GAPIYA JEANNE	ANSS - BURUNDI	BP 4152 Bujumbura BURUNDI Tel: (257) 21 5977/ 24 1501 E-mail: anss@cni.cbinf.com
M'BOA LILIANNE	LUMIÈRE ACTION - COTE D'IVOIRE	14 PB 1201 Abidjan 14 COTE D'IVOIRE Fax: (255) 39 7312 E-mail: Lumiere-action@ci.reflea.org
SLAVA VASSILJEV	ESPO SOCIETY - ESTONIA	Narva Str. 48 Tallinn, 10150 ESTONIA Tel: 372 6455555 Fax: 372 627351 E-mail: aids@ANET.EE
ALMAZ GEBRU	UNV - GERMANY	Postfach 260111 53153 Bonn GERMANY Tel: (49-228) 815 2209 Fax: (49-228) 815-2009 E-mail: Almaz.Gebru@unv.org
CELINA D'COSTA	INP+ - INDIA	29/2 Velu Street, West Mambalam Chennai 600033 INDIA Tel: (91) 44 371 1276 Fax: (91) 44 489 3454 E-mail: inpplus@vsni.com
SUZANA MURNI	SPIRITIA FOUNDATION - INDONESIA	Jalan Lauser No. 3-B Jakarta 12120 INDONESIA Tel/Fax: 62 21 723 5236 E-mail: spiritia@rad.net.id
MICHAEL ANGAGA	NAP+ SECRETARIAT - KENYA	E-mail: nap@africaOnline.Co.Ke

NAME	AFFILIATE & COUNTRY	CONTACT DATA
DOROTHY ODHIAMBO	NAP+ SECRETARIAT - KENYA	E-mail: nap@africaOnline.Co.Ke
MAJOR REBECCA NZUKI	SALVATION ARMY - KENYA	Territorial Headquarters: PO Box 40575 Nairobi, KENYA Tel: 0222 7541
SALVADOR MAZIVE	ASSOCIACAO KINDLIMUKA - MOZAMBIQUE	R. Resistencia 630 C. Postal 1876 c/o UNAIDS Maputo MOZAMBIQUE Tel/Fax: 422 651 E-mail: Unaids@virconn.com
JOSEF SCHEICH	GNP+ - THE NETHERLANDS	PO Box 11726 103165 Amsterdam THE NETHERLANDS E-mail: gnp@gn.apc.org
MOUSTAPHA GUEYE	AFRICASO/ENDA - SENEGAL	P. O. Box 3370 Dakar SENEGAL Tel: 221 823 1935 Fax: 221 8236615 E-mail: moustafa@enda.sn
NKULULEKA NXESI	NAPWA - SOUTH AFRICA	258 Nxiweni Section Tembisa 1628 SOUTH AFRICA Tel: 27 12 40 441 0111 E-mail: napmb@sn.apc.org CELL: 083 4789462
DAN ODALLO	UNAIDS ITC/ESA - SOUTH AFRICA	PO Box 6541 Pretoria 0001 SOUTH AFRICA 351 Schoeman Street Tel: 27 12 338 50 80 E-mail: dodallo@un.org.za
KGOBATI MAGOME	GIPA PROGRAMME - SOUTH AFRICA	PO BOX 13113 Tramshed 0126 SOUTH AFRICA Tel: 27123385212 Fax: 27 12 320 1503 E-mail: kmagome@un.org.za
DAVID MILLER	UNAIDS - SWITZERLAND	20, Avenue Appia 1211 Geneva 27 SWITZERLAND Tel: (41 22) 791 4561 Fax: (41 22) 791 4741 E-mail: millerd@unaids.org

NAME	AFFILIATE & COUNTRY	CONTACT DATA
SALVATOR NIYONZIMA	UNAIDS - SWITZERLAND	20, Avenue Appia 1211 Geneva 27 SWITZERLAND Tel: (41 22) 791 4448 Fax: (41 22) 791 4741 E-mail: niyonzimas@unaids.org
NOERINE KALEEBA	UNAIDS - SWITZERLAND	20, Avenue Appia 1211 Geneva 27 SWITZERLAND Tel: (41 22) 791 4601 Fax: (41 22) 791 4741 E-mail: kaleeban@unaids.org
ANDREW DOUPE	UNAIDS - SWITZERLAND	20, Avenue Appia 1211 Geneva 27 SWITZERLAND Tel: (41 22) 791 4765 Fax: (41 22) 791 4898 E-mail: doupea@unaids.org
SANYA UMASA	WEDNESDAY FRIENDS' CLUB - THAILAND	Wednesday Friends' Club The Thai Red Cross AIDS Research Centre 1871 Rama Road Patumwan, Bangkok 10330 THAILAND Tel: +662 2 255 7893 Fax: + 662 255 7894 E-mail: sanya@redcross.or.th
BEATRICE WERE	NACWOLA - UGANDA	PO Box 4485 Kampala UGANDA Tel: 256 41 269 694 Fax: 256 41 269 694 E-mail: nacwola@infocom.co.ug
MILLY KATANA	NGEN+/NAP+/GNP+ - UGANDA	PO BOX 10028 Kampala UGANDA Tel: 256 41 343301 E-mail: ngen@infocom.co.ug
ESTHER MOSINGHI	ICW SECRETARIAT - UNITED KINGDOM	2C Leroy House - 436 Essex Road London NI 3QP UNITED KINGDOM Tel: 44 20 7704 0606 Fax: 44 20 7704 8070 E-mail: info@icw.org
RON MACINNIS	GLOBAL HEALTH COUNCIL - USA	1701 K Street NW - Suite 600 Washington DC 20006-1503 USA Tel: + 1 202 833 5900 Fax: + 1 202 833 0075 E-mail: rmacinnis@globalhealth.org